

Approach to End of Life Care

David H. Lee, MD, MBA

*Section on Hospital-Based Medicine, Department of Internal Medicine, Ochsner Clinic Foundation,
New Orleans, LA*

End of life care is often overlooked in busy day-to-day medical practice. Physicians need to recognize that death is inevitable for many medical conditions despite aggressive treatment. Optimal end of life care begins with an honest discussion of disease progression and prognosis. By coordinating the care with the family and a hospice program, terminally ill patients can achieve relief of pain and other unwanted symptoms, leading to a good quality of life during their remaining days.

Lee DH. Approach to end of life care. The Ochsner Journal 2002; 4:98-103

End of life care is an important topic that unfortunately has been overlooked in the past. In the process of striving to achieve better understanding and treatment of medical conditions, modern medicine often fails to recognize the inevitability of disease progression despite aggressive medical management. The result is that physicians sometimes fail to provide adequate supportive care for their patients near the end of life. It must be recognized and emphasized that the spectrum of patient care includes appropriate care for patients who are terminally ill in addition to preventive care, diagnosis, and medical care (Figure 1).

Terminology

Terminally ill patients are those whose expectancy is relatively short and whose treatment has shifted from a curative regimen to supportive or palliative care. The World Health Organization defines palliative care as “the active total care of patients whose disease is not responsive to curative regimen” (1). The goal is to achieve the highest quality of care for the patient and family. It affirms the sanctity of life and regards death as a normal process; neither hastens nor postpones death; provides relief from physical and psychological sufferings; and offers a support system to help the patients live as actively as possible and the family cope with bereavement. Hospice care is the final chapter of palliative medicine. It provides support and care for persons in the last phases of terminal illness, usually in the setting of home or hospice residential facilities.

History of the End of Life Care Movement

Prior to the 20th century, the family commonly provided end of life care at home with the assistance of visiting health care professionals. The rise of the modern hospital system shifted the setting of care to the hospital. Despite advances in medical technology, this shift resulted in medical care lacking adequate compassion and dignity for patients. Noting the “death house” environment with depressed, narcotized, and bedridden patients in London, Dr. Cecily Saunders started the modern end of life movement by establishing the first formal hospice program at St. Christopher’s in 1967 (2). In the same period, Dr. Elizabeth Kubler-Ross sought to understand the psyche of the dying patient by describing the psychological stages of dying. She also advocated home, rather than the intensive care unit, as the place of “good death” (3). In the United States, Florence S. Wald developed the first home-based hospice program in 1977 (4).

The advent of modern end of life care in the United States coincided with key decisions by the Supreme Court and Congress. In 1976, the Quinlan case permitted the removal of the ventilator from a comatose young woman. In 1982, Congress authorized the hospice benefit for Medicare. The Cruzan case of 1990 affirmed the right of the patient to have advance directives and to refuse medical care. Following this ruling, Congress passed the Patient Self-Determination Act to encourage advance directives. In 1994, the state of Oregon legalized physician-assisted suicide. In response, the Supreme Court ruled that there is no constitutional right to physician-assisted suicide and allowed states themselves to legalize or prohibit such activities.

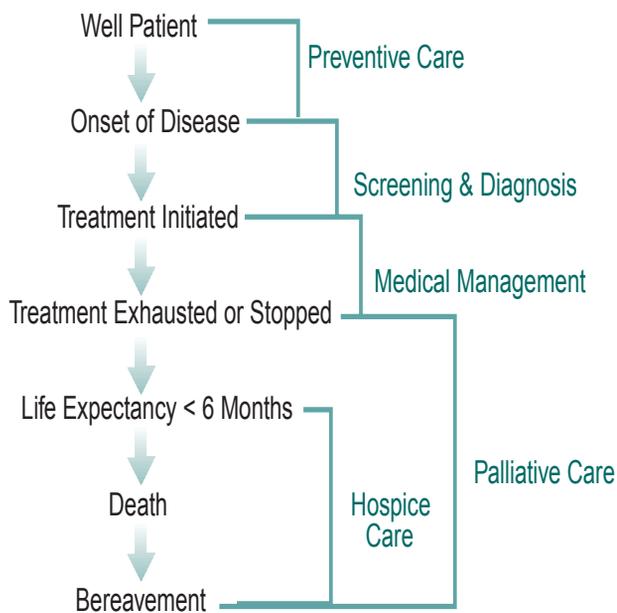


Figure 1. Spectrum of patient care.

Current State of End of Life Care

Despite the progress made in the past 3 decades, the current state of end of life care in the US is still less than satisfactory. Even though most terminally ill patients prefer to die at home, most end up dying in the hospital. Hospice programs have improved the quality of end of life care, but a substantial number of referrals are still made by physicians during the final stages of terminal illness with, according to one study, 15% of patients dying within 7 days of referral (5).

Nearly half of Americans who live to the age of 65 will enter a nursing home before they die (6). Despite this, hospice is rarely used in the nursing home. In 1997, only 13% of hospice enrollees were in nursing homes while 87% were in private homes, and 70% of nursing homes had no hospice patients (7).

Physicians have been criticized for not adequately relieving pain and other symptoms in terminally ill patients. A review of 103 children who had died of cancer concluded that 89% of the children suffered “a lot” or “a great deal” from at least one symptom in their last month of life (8). The quality of communication between physicians and their patients also does not meet the standards proposed in the literature. One study found that

Table. Current myths and realities. Reprinted with permission from (11): JAMA 2001; 284:2495-2501. Copyrighted 2001, American Medical Association.

Myth	Current Status
Forgoing life-sustaining treatment for patients without decision-making capacity requires evidence that this was the patient’s actual wish.	Such treatment may be forgone if the patient’s surrogate relates that this was the patient’s actual wish or, in most states, if it was the patient’s probable wish. Only a few states require “clear and convincing” evidence of patient wishes. In a few states, it is even permissible to terminate life support with the surrogate’s permission if the patient’s wishes are not known, if the termination of treatment is in the patient’s “best interests.”
Withholding or withdrawing of artificial fluids and nutrition from terminally ill or permanently unconscious patients is illegal.	Like any other medical treatment, fluids and nutrition may be withheld or withdrawn if the patient refuses them, or in the case of an incapacitated patient, if the appropriate surrogate decision-making standard is met.
Risk management personnel must be consulted before life-sustaining medical treatment may be discontinued.	There is no legal requirement that a risk manager be consulted before making end of life decisions, though some hospital policies may require it.
Advance directives must comply with specific forms, are not transferable between states, and govern all of a patient’s future treatment decisions. Oral advance directives are unenforceable.	Advance directives, often the best indication of an incapacitated patient’s wishes, may guide end of life decision-making even if all legal formalities are not met. A living will or surrogate should not be consulted if the patient retains decision-making capacity unless expressly authorized by the patient. Oral statements previously made by the patient can also be legally valid advance directives.
If a physician prescribes or administers high doses of medication to relieve pain or other discomfort in a terminally ill patient, resulting in death, he/she will be criminally prosecuted.	If a patient inadvertently dies from the use of high doses of medication intended to treat pain, the physician has not committed murder or assisted suicide.
When a terminally ill patient’s suffering is overwhelming despite palliative care, and he/she requests a hastened death, there are no legally permissible options to ease suffering.	Although physician-assisted suicide is illegal in most states, terminal sedation is a legal option to treat otherwise intractable symptoms in the imminently dying.
The 1997 Supreme Court decisions outlawed physician-assisted suicide.	Physician-assisted suicide is currently legal in Oregon. Other states are free to legalize or prohibit it.

conversations about advance directives averaged only 5.6 minutes and physicians spoke for two-thirds of this time. In addition, the discussion infrequently dealt with patients' values and attitudes toward uncertainty (9). More public education on end of life care is also needed since most patients do not appear to understand end of life care options (10).

On the encouraging side, more coverage on end of life care is appearing in the medical literature, news, and media. There have also been increasing numbers of grants and initiatives for end of life quality improvement.

Legal Barriers to End of Life Care

Many health care professionals have misconceptions regarding the legality of providing or withdrawing care for terminally ill patients. The American College of Physicians-American Society of Internal Medicine (ACP-ASIM) End of Life Consensus Panel has identified seven legal barriers due to myths about the laws pertaining to terminally ill patients (Table) (11).

Determining Prognosis

The prognosis of a patient with a life-limiting disease should be estimated according to the best available medical data, and physicians should be honest and forthright in discussing this information with the patient and family. The prognoses of malignant diseases can usually be determined from the staging of the disease. The prognoses of chronic nonmalignant diseases must be based on clinical progression as documented by serial medical assessments, history of multiple emergency room visits or hospitalizations over the past 6 months (or nursing assessment of progression in homebound patients), and a recent decline in functional status as determined by clinical assessment, decreased performance test results, and a high dependence during the activities of daily living. Documented recent impairment of nutritional status related to the terminal process can also be utilized for assessment. The National Hospice Organization has published medical guidelines to help physicians determine prognosis in selected noncancer diseases (12).

Initiating End of Life Discussions

Initiating end of life discussion with the patient and family is one of the physician's most important roles. Urgent indications to initiate discussion include imminent death, talk about wanting to die, inquiries about hospice care, recent hospitalization for severe progressive illness, and severe suffering and poor prognosis. End of life preparation and options should be a routine part of the discussions of prognosis in life-threatening illness, treatment with low probability of success, patient's hopes and fears, and in cases where the physician would not be surprised if the patient died within 6-12 months (13).

End of life discussion should emphasize the quality of life and the relief from undesirable symptoms. Specifics of the discussion should include advance directives, do not resuscitate (DNR) orders, life-sustaining measures (mechanical ventilation, feeding tube, IV hydration, antibiotics, and kidney dialysis), and palliative care issues such as symptoms management, psychological healing, and spiritual concerns (13).

Dying Person's State of Mind

While discussing end of life issues, health care professionals must understand the dying person's state of mind (14). The first mental stage in a dying person is denial and isolation. Hearing the bad news, the patient is often unable to accept or assimilate the facts of the illness. The patient may go on to distort the interpretation of the facts of the disease and deny the presence of impending death. The second stage is anger when the patient expresses his or her anxiety through anger or other emotions. The third stage is bargaining. The patient may try to strike a bargain, usually with a higher entity, in an attempt to return to normal. The fourth stage is depression when the patient is saddened after realizing the inevitability of death. The final stage is acceptance in which the patient accepts death and moves to a new psychological level.

It is important to recognize that the dying person has lost the most important variance in life – the unpredictability of death. To die in a "healthy" fashion, the dying person must have control of medical care, the right to hear painful truth, time to review the past, the right to maintain a good sense of humor, the presence of significant others, and opportunities to talk about spiritual issues (15).

When discussing dying, physicians should be fully aware of the emotional and physical changes that occur during the dying process. Normal and abnormal reactions of the dying person and family should be recognized and responded to appropriately. In addition, to empathize with the patient and family, physicians need to understand their own reactions to the dying process (15).

Preparing the Patient for End of Life Care

Preparing the patient and family for end of life care begins with an honest discussion of the patient's disease and its outcomes, followed by listening to the patient's needs (12). A foundation of trust with the patient and the family or caretakers is crucial. When delivering difficult news for the first time, physicians should choose a private area and sit down with the patient, family, and caregivers. Plain language is used to offer an overview of the situation, the diagnosis, and its implications, while making no assumptions about what the patient understands.

Physicians should be prepared to repeat the information several times if necessary and allow ample time to recognize the patient's emotional reactions and display their empathy. The specific concerns of the patient and family should be individually addressed. Without overwhelming the patient and family, physicians should provide options such as hospice and offer a general estimate of length of survival. Common questions from the patient and families include (12):

1. Does this mean there's nothing more we can do? Explain that this is not an end to treatment but a shift to intensive palliative care focusing on helping the patient live the rest of his or her life to the fullest.

2. What about pain? Explain that one of the goals of palliative care is effective pain management and that a wide variety of medically sound options are available.

3. What should we do next? State that you will provide palliative care to the patient and contact a hospice program for further care.

The Institute for Healthcare Improvement recommends that physicians make the following promises to a dying patient (16):

1. Promise good medical care
2. Promise no overwhelming symptoms
3. Promise continuity, coordination, and comprehensive care
4. Promise no surprises
5. Promise your wishes will be sought and respected
6. Promise to make the best of every day

Many reference materials are available for patients and families from hospice programs. Further information can be obtained on the Internet (e.g. National Hospice & Palliative Care Organization's website: www.nhpco.org) and from books on hospice care such as *Handbook for Mortals: Guidance for People Facing Serious Illness* (17).

The Hospice Program

When placing a referral to a hospice program, health care professionals should explain to the patient and family that hospice is a comprehensive system of care in which they can find relief from the pain and suffering associated with dying (18). The entire family is the unit of care and the goal is securing the greatest possible degree of physical and spiritual comfort. In the hospice program, care is provided by an interdisciplinary team that includes bereavement support for family members after death has occurred. Typically, the hospice team consists of an attending physician, the hospice medical director, a primary nurse and nurse coordinator, a social worker, a chaplain, volunteers, and other professionals as needed. Primary care physicians may have as much or as little involvement in

continuing patient care as they choose. A hospice program may be an independent organization or a division of a home health agency, hospital, nursing home, or other agency.

Financial Aspects of End of Life Care

In the US, Medicare covers the majority of hospice care, followed by private insurance and Medicaid. A patient is eligible to receive Medicare hospice benefits if 1) the patient is eligible for Medicare Part A, 2) the patient's physician and the hospice medical director certify that the patient is terminally ill with a life expectancy of 6 months or less if the disease runs its normal course, 3) the patient signs a statement electing hospice care instead of standard Medicare benefits for the terminal illness, and 4) the patient receives care from a Medicare-certified hospice program. Eligible patients are entitled to receive two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods with recertification requirements. These periods may be used consecutively or at intervals, but the patient must be certified as terminally ill at the beginning of each benefit period. Hospice services covered include on-call, physician, nursing, social, therapy, home health, and counseling services. In addition, medical supplies and equipment and drugs for symptom management related to the palliation of the terminal illness are also covered.

The majority of Medicaid hospice benefits are modeled after Medicare. For private insurance, the benefit is usually achieved through specific hospice benefit or through a home health care benefit.

Forgoing Medical Treatment

Discussion about forgoing or withdrawing medical treatment is one of the most difficult topics for physicians. However, it is essential that physicians initiate the discussion when starting end of life care and continue the discussion during the rest of the patient's life. Benefits and burdens should be balanced against each other when deciding upon whether or not to continue with tube feeding, IVs, ventilator breathing, or resuscitation. Explain to the patient and family that the natural progression of terminal disease will prevent patients from eating, drinking, or breathing normally. Stopping treatments that replace these natural functions only allows the disease to follow its natural course. Offering food has been a sign of caring and hospitality in many cultures; some people feel that if they stop a treatment such as feeding tube or ventilator, then they will have 'killed' their loved ones (17). Patiently explain that there comes a time when it might be more compassionate to allow dehydration to occur. Forcing tube feedings and IVs on dying patients can make the last days of their lives more uncomfortable.

Nutrition and Hydration

There is no evidence that improving nutritional intake in terminally ill patients has any beneficial effects on morbidity or mortality. The goal is to improve the quality of life by allowing maximal enjoyment from eating. Commercial nutritional supplements should be avoided because they suppress appetite and replace foods the patients normally enjoy. Explain to the patient and family that force-feeding a dying patient will only tire the patient and that eating will not reverse the underlying terminal disease process, that loss of interest in food is natural near death, and that the body can only take in what it needs. Potential benefits of not using tube feeding and IVs near death include (17):

- * Less fluid in the lungs, thus easier breathing
- * Less fluid in the throat, thus less need for suction
- * Less pressure on tumors, thus less pain
- * Less frequent urination, thus less risk of skin breakdown and bed sores
- * Increase in the body's natural pain-relieving hormones, thus increased comfort and less pain

If, despite explanation, the patient or family is still uncomfortable about withholding artificial hydration, then time-limited trials can be offered for the family to determine if artificial nutrition or hydration can improve the patient's quality of life.

Ventilators

Ventilators often save lives. However, in patients with terminal illness a ventilator may cause more harm and suffering. Reasons not to use the ventilator include (17):

- * It can be hard for a terminally ill patient to recover enough to come off the ventilator
- * Ventilators do not reverse the disease process
- * Ventilators may interfere with ability to speak and swallow
- * Ventilators are uncomfortable
- * Extra sedation may be required on the ventilator
- * Many blood test and X-rays may be needed for monitoring while on the ventilator.

Resuscitation

Disrupting the body with invasive activities at the time of death, resuscitation may be worthless and unnatural. This is especially disturbing for patients near the final phases of their illnesses.

Control of Unwanted Symptoms of Dying

One of the major goals of palliative care is to relieve the dying patient from unwanted symptoms. Symptoms requiring a variety of

medical interventions near the end of life include pain, dyspnea, anorexia-cachexia, constipation, nausea, neurologic changes, and psychological distress (4). Practical medical references on palliative care include the *Hospice and Palliative Care: Concepts and Practice* (15) and *Oxford Textbook of Palliative Medicine* (19).

Pain is the most common and fearful complaint of the dying patient and physicians have been criticized for not adequately relieving pain. In 1990, the World Health Organization emphasized its "ladder approach" to pain management (1). The basic principle of optimal pain management dictates the use of a simple dosing schedule. Nonsteroidal anti-inflammatory drugs (NSAIDs) are first-line for mild to moderate pain. If the pain increases, an opioid or an NSAID-opioid combination can be added. When the pain becomes moderate to severe, the opioid strength should be increased. Ideally, pain medications are scheduled around the clock with extra medications prescribed for breakthrough pain. If the patient is unable to take orally administered drugs, parenteral or transdermal routes can be utilized (4). Nonpharmacologic treatments such as complementary medicine with acupuncture and biofeedback may also be recommended as adjunctive therapy if applicable to the patient. To achieve better pain control, physicians must objectively characterize the patient's pain through the use of a pain schedule and determine the patient's goal in patient relief.

Finals Days

Patients and families need to be educated about the normal physiologic response to dying. During the final days of dying, appetite, thirst, and urinary output decrease secondary to the body's inability to assimilate food and fluids, leading to multisystemic failure. Then breathing patterns begin to change. The patient may experience rapid shallow breathing or periods of apnea followed by several deep breaths. Noisy, rattling respiration may occur due to secretions moving up and down at the back of the throat. The level of consciousness decreases and progresses to unresponsiveness (15). At the time of death, caregivers are instructed to call the hospice and funeral home. Instructions regarding autopsy and organ donation should be followed after pronouncement of death according to the patient's wish. Finally, bereavement counseling is offered to the patient's family.

Controversy in End of Life Care

One of the most controversial subjects in end of life care concerns physician-assisted suicide and euthanasia. Euthanasia is the deliberate termination of life in a person with terminal illness. Physician-assisted suicide occurs when that person requires the assistance of a medical professional in obtaining lethal doses of

drugs and instructions for euthanasia. Proponents of euthanasia and physician-assisted suicide argue that it is the patient's right to self-determination and the obligation of health care professionals to relieve suffering (20). However, there are many problems with this argument. Patients who request euthanasia are frequently suffering from pain and other symptoms. Effective relief of these symptoms often results in patient's repudiation of the wish to die. In addition, a patient's request for euthanasia may be a choice they believe others want them to make, or request for euthanasia may be a way of expressing other feelings. In a survey of 988 terminally ill patients, 60.2% supported euthanasia or physician-assisted suicide, but only 10.6% reported seriously considering euthanasia or physician-assisted suicide for themselves. Over a few months, half the patients who seriously considered euthanasia or physician-assisted suicide changed their minds. Patients with depressive symptoms were more likely to change their minds (21).

Is it ever appropriate and morally justified for a health care professional to respond to patient's request for euthanasia? A survey of 3299 oncologists in the US found that attitudes and practices regarding euthanasia and physician-assisted suicide were related to the availability of optimal end of life care and the adequacy of their training in these issues (22). Health care professionals should strive to expand palliative care services, develop better postgraduate medical training, and improve the quality of care at the end of life, so there will not be a need for euthanasia and physician-assisted suicide.

Summary

With continuing advances in and reliance on medical technology, end of life care is often overlooked. Physicians have to recognize that, for certain diseases, death is inevitable despite aggressive treatment. Initiation of end of life care begins with an honest discussion of disease progression and prognosis. By coordinating the care with the family and a hospice program, terminally ill patients can achieve relief of pain and other unwanted symptoms, leading to a good quality of life for their remaining time.

References

- World Health Organization. Cancer Pain Relief and Palliative Care. Technical Report Series No. 804. Geneva: World Health Organization, 1990.
- Liegner LM. St Christopher's Hospice, 1974. Care of the dying patient. *JAMA* 1975; 234:1047-1048.
- Kubler-Ross E. *On Death and Dying*. New York: Macmillan Publishing Company, 1969.
- Kaur JS. Palliative care and hospice programs. *Mayo Clin Proc* 2000; 75:181-184.
- Christakis NA. Timing of referral of terminally ill patients to an outpatient hospice. *J Gen Intern Med* 1994; 9:314-320.
- Kemper P, Murtaugh CM. Lifetime use of nursing home care. *N Engl J Med* 1991; 324:595-600.
- Zerzan J, Stearns S, Hanson L. Access to palliative care and hospice in nursing homes. *JAMA* 2000; 284:2489-2494.
- Wolfe J, Grier HE, Klar N, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med* 2000; 342:326-333.
- Tulsky JA, Fischer GS, Rose MR, et al. Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med* 1998; 129:441-449.
- Silveira MJ, DiPiero A, Gerrity MS, et al. Patient's knowledge of options at the end of life: ignorance in the face of death. *JAMA* 2000; 284:2483-2488.
- Meisel A, Snyder L, Quill T. Seven legal barriers to end-of-life care. Myths, realities, and grains of truth. *JAMA* 2000; 284:2495-2501.
- Hospice Care: A Physician's Guide. Arlington, VA: National Hospice Organization, 1998.
- Quill TE. Perspectives on care at the close of life. Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room." *JAMA* 2000; 284:2502-2507.
- Lair GS. *Counseling the Terminally Ill: Sharing the Journey*. Washington DC: Taylor & Francis, 1996.
- Sheehan DC, Forman WB, eds. *Hospice and Palliative Care: Concepts and Practice*. Sudbury, MA: Jones and Bartlett Publishers, 1996:107-114.
- Lynn J, Schuster JL, Kabcenell A. *Improving Care at the End of Life: A Sourcebook for Health Care Managers and Clinicians*. Oxford: The Center to Improve Care of the Dying, Institute for Healthcare Improvement, Oxford University Press, 2000. www.ihl.org/resources/eol/promise.asp.
- Lynn J, Harrold J. *Handbook for Mortals: Guidance for People Facing Serious Illness*. New York: Oxford University Press, 1999:129-138.
- Asch-Goodkin J. The virtues of hospice. *Patient Care* 2000; November 15:72-91.
- Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*, 2nd Ed. New York: Oxford University Press, 1998.
- Snyder L, Sulmasy DP. The Ethics and Human Rights Committee, American College of Physicians - American Society of Internal Medicine. Physician-assisted suicide. *Ann Intern Med* 2001; 135:209-216.
- Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000; 284:2460-2468.
- Emanuel EJ, Fairclough D, Clarridge BC, et al. Attitudes and practices of U.S. oncologists regarding euthanasia and physician-assisted suicide. *Ann Intern Med* 2000; 133:527-532.



Dr. David H. Lee is a practicing hospitalist at the Ochsner Clinic Foundation.